

Mental health care for people with mental retardation: a global perspective

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There has been a transformation in the care of people with mental retardation since the late 1960s. One of the most important changes has been the movement towards integration, participation and choice for people with mental retardation, being a facet of larger disability, civil, and human rights movements internationally and within nations. This movement has usually formalised in the activities of charitable or advocacy organisations, or consortia of such groups. These have pursued legal challenges to rights deprivation at the national or local level, engagement with bureaucrats involved in policy development, and participation at all levels of the mental retardation service system.

Advances in a number of fields and disciplines, including genetics, psychopharmacology, developmental neuropsychiatry, psychology, and education have also shown promises for improving the treatment and lives of people with mental retardation. In addition, the provision of more appropriate models of social care has had a substantial impact in improving the quality of life of people with mental retardation in community settings, and enabling staff, carers and families to be more involved and more effective.

People with mental retardation represent a heterogeneous group with a varied range of highly complex needs. The different professions involved in this area have diverse perspectives about people with mental retardation, each giving inconsistent and ambiguous terms and categories. In addition, most cultures use ill-defined and changeable social labels, which are either stigmatising or promoted as non-stigmatising. As a result, it is very difficult to be assured that the groups identified in various nations as having mental retardation are comparable, with some definitions potentially encompassing larger segments of the population than others. As well, different terms are used in different countries. In the United Kingdom the Department of Health replaced the term 'mental handicap' with 'learning disability' in the early 1990s, without taking into consideration the different connotation of the term in the rest of the world. The American Association of Mental Retardation decided in

1993 that the term 'mental retardation' should stay, and re-defined it as a significantly sub-average intellectual functioning existing concurrently with related impaired limitations in two or more of the following areas of skills: communication, health care, home living, social skills, community, self-direction, health and safety, functional, academic leisure and work, manifest before the age of 18. 'Developmental disabilities' is also used, instead of mental retardation, mainly in Australia and Canada. In recent years, the term 'intellectual disability' has been adopted by some international organisations and is gaining ground as an 'international term' for people with mental retardation.

SERVICE DEVELOPMENTS FOR PEOPLE WITH MENTAL RETARDATION

Services provided for people in Westernised nations are similar, usually publicly funded, and encompass residential accommodations, productive day involvement, supportive services such as respite or parent training, and some clinical services. Substantial numbers of people are registered on public waiting lists for residential accommodation, as developments lag behind demand to varying degrees in different nations, provinces or states. Commonly, both public agencies and charitable organisations provide service, with a tendency for public agencies to provide institutional or highly specialised (e.g., intensive care) services and charitable organisations to provide supportive services. There has also been a trend for delivery of a wide range of residential, especially community residential, day, clinical, and supportive services from the public to the charitable sectors.

Residential options can include specialised institutional settings, non-specialised institutions (e.g., nursing care or mental health facilities), group homes serving from a handful to 10-15 people each, specialised and non-specialised foster care, supportive apartment living with drop-in supervision, and for some, home purchase subsidies. Day options can include a range of organised programs addressing habilitative,

prevocational, vocational preparation, adult educational, and competitive or assisted employment. Day services can be highly individualised, or provide relatively non-individualised programs, and be either centre-based, or distributed in their activities throughout communities. Clinical services are often provided by hospitals, speciality clinics, community clinics, university-based clinics, and by charitable organisations. In some instances, professionals who are public employees may supplement specific clinical services in short supply. Supportive services, which have grown massively in their availability and variety in the past 15 years, are typically provided on demand and in a tailored manner by charitable organisations.

There are significant differences in the availability and character of mental retardation services not only among nations, but also among provinces or states within nations and among localities in provinces or states. These differences reflect variations in national and local policies, historic levels of public financial commitment to health and social services, cultural considerations, and competing federal and local priorities for utilisation of scarce public funding. Differences in the availability of services can differ as extensively among localities and states as among nations.

International organisations of individuals and agencies serving people with mental retardation have not typically developed guidelines for service systems. Instead, there have been guidelines developed with international applicability with respect to specific goals or clinical concerns, such as use of psychotropic medications (1), and the assessment and diagnosis of mental health problems (2). There have also been United Nations documents, such as the Universal Declaration of Human Rights, the Declaration on the Rights of Mentally Retarded Persons, and the Declaration on the Rights of Disabled Persons. Most Westernised nations have national policies regarding mental retardation services, and funding mechanisms that are focused on providing services and supports to people with mental retardation. In some instances, however, these two efforts are not closely integrated, in the sense that the priorities identified in policy may not be addressed in funding streams or may require use of resources from multiple funding streams. In such instances, implementation of policy may lag behind its adoption, and changes in service delivery, to a significant degree.

COMMUNITY LIVING

In the USA, the number of institutionalised people with mental retardation decreased drastically in public institutions and state psychiatric facilities, falling by 23% between 1967 and 1976 and by 46% from 1976 to 1996. International changes in the use of institutional care from 1981 to 1991 showed great diversity: rates of annual decrease in the use of institutions were from -1.6% to -5.9% in Scandinavia, from +0.4% to -5.0% in the European Community, +0.6% in Eastern Europe, and -3.3% in the USA (3).

Utilisation rates for mental retardation institutions in the USA, 1998 ranged from 0.0 in 10,000 general population in four states to 5.1 in 10,000 (4). A total of 15.5 in 10,000 were receiving residential care, with 57% served in settings for six or fewer people, and 30% served in settings for 16 or more people. Of this latter group, 42% were served in specialised mental retardation facilities and the remainder in non-specialised facilities, including a small proportion, perhaps as many as 7%, who may be living at mental health facilities.

Approximately one in five mental retardation institutional residents in the USA has a co-occurring mental disorder, and costs for care attributable to these individuals are twice those of their peers in the same residential contexts (5). This finding suggests that in some states as many as 1.2 per 10,000 people with mental retardation and co-occurring mental disorder may be served in institutions, and at lower rates in various other types of more integrated residential settings. However, with continuing shifts in the USA to utilise smaller settings, it has become more likely that the majority of people with both mental retardation and mental disorders will live in these smaller settings in many states.

The development of a wide range of residential settings, respite care, daytime activities, employment opportunities and mainstream education, have all been major achievements for people with mental retardation and their carers. A wealth of literature has demonstrated that institutional closure can be achieved with a variety of positive outcomes for those residents concerned (6). However, people with mental retardation resettled into community establishments without very careful planning can become understimulated and withdrawn, and their psychiatric and behavioural problems may become more overt (7).

MENTAL HEALTH NEEDS

The term mental health needs refers to people with mental retardation who have any psychiatric diagnosis included in any of the international classification systems or a behaviour disorder requiring psychiatric intervention. People with mental retardation are estimated to be three to four times more likely than those in the general population to experience an emotional, behavioural or psychiatric disorder (2).

The assessment and diagnosis of mental health problems in people with mental retardation has improved with the development of specific diagnostic tools. Our knowledge of the clinical presentation of psychiatric disorders in people with mental retardation has also increased. The association between certain behavioural disorders and specific genetic syndromes has opened up the possibility of different treatment approaches. Recent advances in molecular genetics have provided further evidence that specific syndromes of mental retardation are associated with a behavioural phenotype (8).

As the life expectancy of people with mental retardation has increased significantly, substantial numbers of them are now living well into old age and presenting similar mental and physical health problems and care needs as the elderly population (9).

The realisation that the full range of therapeutic interventions employed in general psychiatry can be utilised, adapted as necessary, in the treatment of psychiatric disorder in people with mental retardation has created an atmosphere of therapeutic optimism (10).

In some parts of the world, such as the UK, there are psychiatrists and psychologists specialising in the mental health problems of people with mental retardation. In many countries, however, this is not the case, and general psychiatrists, paediatricians and other professionals without special knowledge of their problems, may look after people with both mental retardation and mental disorders. In the USA, where it is common for states to operate separate and distinct sectors for public mental retardation and mental health services, special concerns arise regarding increased needs for co-ordination and integration of joint care across these sectors, as well as among service organisations and clinicians.

The interest in the mental health problems of people with mental retardation has established the Psychiatry of Mental Retardation as a distinct psychiatric speciality in an increasing number of countries. There has also been a corresponding growth in service developments, staff training, care and treatment, research, specialist textbooks and journals, international organisations and conferences devoted to the subject.

The international initiatives include the work of the WPA Section on Mental Retardation since the 1979; the National Association for the Dually Diagnosed in the USA since 1983; the European Association for Mental Health in Mental Retardation since 1992; and the establishment of a Special Interest Research Group in Mental Health by the International Association for the Scientific Study of Intellectual Disability in 1998.

Specialist publications have appeared in recent years to raise awareness and promote evidence-based practice in the field. The WPA Section on Mental Retardation published 'Mental Health in Mental Retardation: the ABC for Psychiatrists, Primary Care and Other Professionals' (11), which has been translated into Italian and Spanish. The European Association for Mental Health in Mental Retardation published the Practice Guidelines for Assessment and Diagnosis of Mental Health Problems in Adults with Intellectual Disability (2). The WPA Section on Mental Retardation has launched a new publication at the 12th World Congress of Psychiatry in Yokohama entitled 'Autism and Related Disorders' (12). The National Association for the Dually Diagnosed in the USA has recently developed a comprehensive training resource manual on mental health and mental retardation, providing trainers with guidance in selection of training for physicians, other clinicians, managers and

administrators, and case managers (13). The Journal of Intellectual Disability Research has also been publishing two special issues per year since 1998 on the mental health problems of people with mental retardation.

SPECIALIST SERVICES

The fundamental changes in the philosophy of care and clinical advances have highlighted the need for new service systems to support people with mental retardation to live in the community. Specialist services maximise staff skills and competencies, increasing the probability of effective and successful treatment, and provide a base for teaching, training and research. Attempts to provide mainstream psychiatric services for people with severe levels of mental retardation have proved less than successful. Evidence based research is, however, very patchy. Evaluation of current provision is therefore necessary to identify the most effective forms of service provision and in developing 'best-practice' guidelines (14).

A growing number of specialist mental health inpatient units for people with mental retardation, linked with mental health services, seems to have started in various parts of the world (e.g., Massachusetts, New York, London, Hong Kong). Although some of these services are not well integrated with community care organisations, often their main aim is to promote continuity of care and to support different community programs for people with mental health problems and mental retardation.

A concerted action project of the European Union examined the strengths and weaknesses of mental retardation services in five European countries: Austria, England, Greece, Ireland and Spain (15). Several gaps were identified particularly in relation to generic mental health service provision. In many cases service provision to this group of people is ad hoc and dependent on the good will and the personal commitment of the professionals and volunteers involved. Policy and legislation tend to separate the disability aspects of people with mental retardation from their mental health needs, which remain largely invisible. It appears that there is a sense of unmet need for people with learning disabilities and mental health needs, which might be a direct reflection of the lack of policy clarity and legislation, or lack of planning, or lack of implementation. The effects on the lives of people with learning disabilities, their families and carers are pernicious.

Staff find working with people with mental retardation and mental health problems stressful. Giving them skills in this area so that, with support, they can manage people with mental health problems enables them to find this work more rewarding. Flexible training materials, which can be used by staff groups in their own settings, are now available (16,17), and distance education opportunities hold promise for expanded delivery of staff education by university-based experts in mental retardation and mental health. Results demonstrated the effectiveness of training

workshops in improving service user mental health, with significant reductions in the number of psychiatric symptoms (18).

CONCLUSIONS

The last decade has seen the development of more individualised empowering and inclusive approaches to services for people with mental retardation. Most of these developments are based on a process of person-centred planning. Self-advocacy supports people with mental retardation taking more control over their lives and helps involving them in decision-making for service planning. However, the mental health needs of those with dual diagnosis continue to be overlooked and remain grossly unmet. More effort is required from all concerned to address this major gap constructively and using evidence-based practices.

The challenge for the future is to maintain this momentum and increasingly improve services. In many countries services are still patchy and variable and in very few there is a clear and comprehensive national policy.

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